

Status Report April 2021

A few years after the transplant I am, as Johnny Winter used to say “Every now and then I know its kinda hard to tell, but I am still alive and well”. I spend time with my wife, grandchildren, work in my garden and tend to my yard. I enjoy reading and writing but am hampered by the following.

Fatigue Physical	Until very recently I could only walk less than half a kilometer before I became exhausted. Recently my endurance has improved dramatically in that I can now walk a few miles every few days.
Fatigue Sleepiness	I often go days without needing a nap, but when my activity level approached 50% of what would be normal I am over exerting and then collapse. I can usually power thru a half hour of physical activity with an hour or more of rest, if I repeat that multiple times in a day I will suffer the next day
Shortness of breath	This comes and goes, I am seeing a cardiologist about it, but it gates almost all of the physical activity.
Mental confusion	When tired I find thinking difficult, the early morning is best and I find the afternoons are best for resting, cooking or yard work.
Loss of hearing	Assorted drugs have played havoc on my hearing, I am now functionally deaf in one ear with a 50% loss of hearing the other, I use a hearing aid. This is mostly from a drug called Lasik
Vision problems	I am developing blind, fuzzy spots in my left eye I am scheduled to see an eye doctor about it, it makes me a bit cross eyed as I favour the good eye. Just add a hump on my back and I will be quasimoto
Weight Gain	I have put alot of weight on from the use of Prednisone and the inactivity of fatigue and the various blood pressure pills that cause retention or loss of water.
Trauma / Guilt	It is a funny place to be in when you know you are lucky to be alive, someone gave you a gift of life and yet you feel overwhelmed by what you went through and feel guilty for not just being grateful. So you power on....
Depression	I am not big on depression, I think its a waste of time and I do have alot of people supporting me, and it is just not me, but occasionally I sigh and do the calculation of cost vs benefit of going on. The numbers are still positive. Stay tuned.
Kidney health	Basically I am a 63 year old male with a kidney of an 80 year old, its working but at about 70% efficiency. I can read the blood work and see stability to a slow decline, because I have very limited contact with doctors from the hospital, I talk to a nurse practitioner every 3 months and a doctors might talk to me for 10 minutes every 6 months. I have no context of where I am in decline.
Feeling of abandonment	I was given a virus infected kidney, it creates a rare disease, no doctor is willing to be the hero for my case, so I get passed off. Epic Capability fail.

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When I look back, I shake my head and laugh at all I have been through, when I think of the process its a bit like a pinball machine, bouncing from one crisis to the next. In the end I am alive and this is good. So I am happy and continue.

Patient	I am a terrible patient, argumentative, opinionated, skeptical, I choose what to believe and not to believe when the doctors give me information and I tend to have to research everything they say myself, I like citing peer reviewed literature and as my family doctor says, “why would I argue with you you are usually better informed about your issue than I am” I like her.
Epic Fail: Dr Posen	My mid 1980’s nephrologist who examined me when PKD was discovered in the family, told me not to worry about it and I did not. On the plus side I had 40 years of not fretting, ignorance is in fact bliss. On the downside if there had been a process to deal with early stage PKD maybe I never would have had to go on dialysis. Not all of capability maturity.
He tried: Dr Bhatia	My family doctor from the 70’s till he retired in the early 2000. He never got my blood pressure under control and I never got the sense that I had any real problems other than he advised I not do martial arts due to impacts on my kidney, I complied.
Epic Fail: Peritoneal Dialysis	After the fact I was told it would probably not work any way because of my size 6’4” 105Kg and the fact that I had an obstructed bowel and the surgery cut into my peritoneum so there was too much scar tissue. Then why try it, a breakdown of process
Epic Fail: Drain Pain	This is a touchy one, when the PD cycler sucks the last of the fluid from your belly it sucks your penis from the inside and hurts like hell. No one tells you about this, then its a mystery, turns out its because the PD catheter is misplaced. Ouch. Another breakdown of process with no corrective action.
Epic Fail: Blood pressure crash PD to HD	Peritoneal Dialysis (PD) lowers your blood pressure so when you go off of Hemo Dialysis (HD) you need to adjust the meds. Did not happen with me and I had horrendously low blood pressure for more than a few weeks and a few trips to emergency. Another epic breakdown of process with no accountability, no one had responsibility, no one paying attention.
Epic Fail: C Difficile	You will never know just how much you can shit until you have C Difficile. Again to the emergency more than once. Apparently caused by being given massive doses of anti biotics which I was lucky enough to enjoy. They did heroics to clean, test and diagnosis but not sure about the root cause analysis and corrective action. None that I have seen.
Epic Fail: Fistula 1	A surgery for vascular access for dialysis that did not work. A shrug of the shoulders and try again. No one that I know of

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	<p>looked into why it did not work. No analysis of the success rate of that surgeon that I am aware of. Just do it again. No accountability.</p>
<p>Epic Fail: Anti rejection drug reactions</p>	<p>The first six months after the transplant was a living hell, the drugs knock you over and the adjustment is harsh. Withdrawal from opiates used as pain killers is terrible and they really don't give you any warning. When I met one of the dialysis doctors in the hall and mentioned how hard it was, her response was "yeah we should warn you" but they don't, epic process fail!</p>
<p>Epic Fail: Anti Viral s</p>	<p>To this day I don't know if they gave me these because they knew the serology mis match was serious. What they said was it is standard as one of their patients had died. What patient, an EBV- patient getting an EBV+ kidney. I never got a strait answer from the revolving door of doctors you see. Epic information fail, process fail and self awareness fail.</p>
<p>Epic Fail: EBV, Chronic EBV, possiblity of PTLD</p>	<p>They state I am better off than being on dialysis, sounds like a pathetic justification to me, at this time I have EBV, Chronic EBV and a chance at PTLD. The actual chance of it I do not know, the doctors do not know, the research is not conclusive, some say a 5% increased risk, some say a 15% risk, some say a 30% but they don't agree on the EBV test, the methods of calculation of risk, the process of analysis or the interpretation of results. This is the lowest level of capability maturity. If I worked in the medical field I would be embarrassed to even discuss the level of capability maturity demonstrated.</p>

- i John Dawson "Johnny" Winter III was an American singer and guitarist. Winter known for his high-energy blues rock albums and live performances in the late 1960s and 1970s. He also produced three Grammy Award-winning albums for blues singer and guitarist Muddy Waters.